



POST POLIO MATTERS

Polio Survivors Network Newsletter
JANUARY 2023 — Volume 10 Issue 12 of 12 [120]



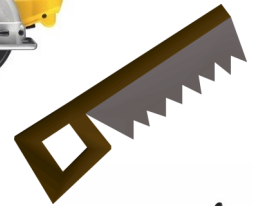
Are you being **LAZY**
using
labour saving devices?



2023

New Year Resolution

To try anything
that might help me
do more of the activities
I would prefer to do




[Lincolnshire Post-Polio Library](#)

Polio Survivors Network is the working name of registered charity 1064177, The Lincolnshire Post-Polio Network

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<u>Donations and Charity Incentives Paid</u> <i>(since last newsletter)</i>	
Donation (J & E Pullin)	£12.50
Donation (D Williams)	£5.00
Donation (A Smith)	£40.00
Donation (A Jackson)	£30.00
Estate of A Brown (final payment)	£46.93
Smile.Amazon	£14.21
Donation (P Galvin)	£12.50
Donation (J Edwards)	£25.00
Donation (Anonymous)	£1.00
Total	£187.14



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Editorial by Hilary Boone

January 1st 2023. The start of the rest of your life doing less of the activities that you think you still need to do by accepting help in any form to manage the harder parts of tasks so that you can do way more of the activities you would prefer to do.

Polio Survivors are renowned worldwide to be pig-headed, strong-willed, do not give up till they have finished a task. When we were recovering from polio we heard folks say things like, "he/she will never be able to do this/that" and we would say to ourselves "Oh yes I/we will" and we pushed ourselves daily and achieved way more than anyone thought we would.

Post-Polio Syndrome's will still overdo things at times even when they have accepted that things such as pacing and resting; using aids and assistive devices; help from someone more able to do the hard part of tasks etc., all allow us to manage our energy levels with less pain and less fatigue. Why do we do this? From experience, I thought that being able to tell my family/carers that I had not waited for them and had hung all the washing out myself was a good thing. However, when they got the courage up to talk to me about things like this they asked how much extra pain did it cause, how many extra hours did you just sit in the chair exhausted, what other tasks that you normally did without help did we have to have help with that day, and would I accept that I had been just a little bit 'snappy' in my answers to their questions and overall had I actually achieved more by doing it? I had to admit that I had actually achieved less that day.

We are all getting older and many have other symptoms/issues to cope with as well. Accepting help to do a task whether it be using a new piece of equipment or someone physically helping or doing the task for us is not easy. If by doing this we are in less pain, have less fatigue and can actually manage to do more of other activities that we would prefer to do... is that not better for us and for those around us? We still need to achieve and I wonder if you have you thought about the skills you have and is there another way you can use these?

Now that life is opening up again [still taking sensible precautions] have you thought about where you might do a talk about your skills or medical needs? Educational establishments, community groups, local charities, etc. We have been part of the Together Group at the University of Lincoln for many years and have shared our lived experience with those training for social and medical careers. We have taken part in Open Days, Interviews, Course planning, Lectures and more. On the plus side we have gained by hearing about the different ways there are of assessing us physically, obtaining information, completing forms etc. Students have asked us things like why do you do this that way. To us it is something we do as part of our normal life but putting it into words has made us realise we can now rephrase our replies to include the why in future.

It is with some sadness as a Founder Member of the Lincolnshire Neurosciences Forum in January 1998 that became the charity Lincolnshire Neurological Alliance that I now report...

Lincolnshire Neurological Alliance to Polio Survivors Network

Dear Member, It is with great sadness that we inform you that the decision has been made to dissolve the Lincolnshire Neurological Alliance as of 31st December 2022.

We have enjoyed the challenge of working with you all to improve the neurological services offered in Lincolnshire and know that there is still a very long way to go. We hope that those of you working with other specific neurological condition charities can continue to push for much needed improvements in neurology in our area. We are sure that although the LNA is no longer able to bring us all together that individually we will all continue to fight for change. Thank you so much for your help and support over the last 24 years and we wish you all the very best.

Kind regards, Lincolnshire Neurological Alliance

January 1998 - Lincolnshire Post-Polio Network [now known as Polio Survivors Network] became Founder Members of the Lincolnshire Neuroscience Forum at the inaugural meeting with the Director of Public Health Lincolnshire Health Authority and other NHS and Social Services staff. A few years later we became the charity Lincolnshire Neurological Alliance. 24 years with continual changes of boundary and/or names of the governing body all promising to act on our constantly repeated request for better services for those of us with neurological conditions in Lincolnshire.... *[continued on [page 10](#)]*

MESSAGE FROM OUR CHAIR



Welcome to 2023!

I want to wish you all a really positive and PPS style healthy 2023 with perhaps a slightly off beat personal note on how, as a psychologist and a disabled person, I know that the way we think, and feel is hugely impacted by our physical health, social situation and finances. This is so often ignored when we seek therapy as it is outside our individual control and down to the environment. So many of us now live daily with anxiety and fear of needing an ambulance or a hospital bed knowing it might not be available this added to the ever-present anxiety that our post-polio and disability is almost certainly not going to be understood or addressed without a struggle.

We are here to help with information and support, But, what can I do now to build my resilience to all this? Last year I returned to an interest in philosophy and history.

*“Be like the cliff against which the waves continually break;
but it stands firm and tames the fury of the water around it.”
(Marcus Aurelius, Meditations)*

I turned to a course about Marcus Aurelius born in Rome in 161AD and died in modern day Vienna in 180AD. He is probably one of the greatest Roman Emperors and philosophers. But interestingly for the times we live in now, from almost the moment he became emperor he was faced with devastating floods, plague and wars and the dealing with his own ill health. I am sure that his many years of philosophical training were what helped him navigate this and become one of the greatest and wisest Emperors of all time despite the adversities he faced.

Essentially modern cognitive behaviour therapy (CBT) is based on stoic philosophy. But going to Marcus Aurelius and reading about his life has helped me in a way that CBT never has. I find more depth and richness in his life than the short-term, generalised, often one-dimensional programmes of CBT available from the NHS and other sources.

So, my suggestion for 2023 is his to read about him and try the ‘Meditations’ where you can become privy to his private reflections and philosophy and see how much of it resonates and how it can offer so much more than much of today’s quick fixes. I hope it might be of practical help for us here and now nearly 2000 years later and of course give us the resilience we need to navigate our lives living with PPS and disability within the UK today.

*“Because a thing seems difficult for you,
do not think it impossible for anyone to accomplish.”
(Marcus Aurelius, Meditations)*

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Your Committee need more help please.

We are not only managing our physical health but getting older with all the paperwork that entails. We know of at least one group where they have two people for each post. If you could spare us an hour or two a month to take on a task then get in touch. Our meetings are held on the Internet but with the facility of adding someone via their phone. All members are welcome to send us any info on anything that might help us manage/enjoy our lives move fully.



My Polio Life - Zsuzsanna Snarey, *PSN Trustee*

Even though I had polio as an 8-year-old child, I had always been very healthy. With the help of my mother, I overcame my disability and coped with life as if I were able-bodied. I was not able to run and had to use a stick but that did not stop me from working. I gained a Chemistry degree at London University and met my husband (also a Chemist). We married and had three beautiful daughters. I became a part time teacher, I kept our house clean and tidy, did the shopping, attended evening classes in pottery, learnt to play the violin and joined an orchestra, later I joined the Manwood Singers and stood for long hours in concerts. I could lift, if not carry, heavy shopping bags, schoolbooks and after retiring from teaching before the age of 60, I became a chiropodist. I managed to lift and pull my chiropody case when visiting people in their homes. I carried on working until past the age of 76 when we moved to Nottingham.

I am quite used to tripping and falling but that does not worry me, I could always get up and hardly ever did any real damage until one day in January 2001 my good knee gave way in the shower, and I cut my right shin on the edge of the shower tray. The wound became infected and had to be dressed in the hospital twice a week. After about four weeks the wound became gangrenous and I nearly had to have a skin transplant, but when I was allowed to dress it myself daily it began to clear up and eventually healed.

In 2005 I was diagnosed with breast cancer and had to stop taking HRT which I believe helped my muscles and my joints because soon afterwards I started a steady decline. I started having joint pains and my stamina decreased dramatically. I had a lumpectomy followed by mastectomy. The two anaesthetics did not help me either. Later the advice about HRT was changed and now it is not stopped for people who had breast cancer. The following year we bought a folding wheelchair to take on holiday which was a liberating experience for both Michael and I and the year after that I had a Pride GoGo electric buggy because I hate being pushed. In 2011 we flew to Budapest with my family and took a small folding buggy, called a Luggie on the plane.

The day before Christmas 2014 I had a nasty surprise, I was diagnosed with Hepatitis C. I have no idea how long I have had the disease which is caught from infected blood. I know that it has harmful effects on the body. It may also have contributed to my failing muscle strength. I could have picked it up in the hospital in 2001 although one doctor suggested that it was caused by the blood transfusions sixty-five years previously when I had polio and was given blood with possible antibodies from a woman who had overcome the disease! I was hoping to have treatment but after two years of fruitless waiting I decided to buy the drug privately from India and took the twelve-week course and I was cured within four weeks. I have by now overcome three possible killer diseases: Polio, breast cancer and Hepatitis C not to mention falling headlong down the stairs three times. My husband insisted on buying a stairlift. So, I have stopped going up and down the stairs which was a very good exercise. It is possible that any one of these influenced my failing mobility, but it is impossible to know which one had the most decisive influence. Another reason for my declining strength is getting older, losing precious neurons daily after the age of fifty.

For quite some time I have been using a wooden stool to do the cooking. I now have a hairdressers' stool on which I can scoot about as well as lower and raise myself. I sit down to use the vacuum cleaner, sometimes on the mobile stool, or a computer chair and I use the mobility buggy for trips to the shops and to cover any distances outside the house. I expect the day will come when I will need a wheelchair even inside the house, but I try and keep going as long as I can without it. I have a UTX swing caliper for each leg. It took many years of persistence to get them from the NHS. Now I am not able to walk more than a few steps without them.

I spend my time in doing mainly sedentary occupations, such as writing, reading, studying mostly on the computer, having spent nearly 18 years looking after people's feet. But I know that too much sitting is not good for me, so to increase my strength I stand up from time to time and also try to do exercises. Of course there is always something more interesting or important to do, so recently I came upon an online physiotherapy App called OneStep and I have been following their exercise regime. I get reminders on my phone and I am in touch with a real physiotherapist who takes note of my particular condition.



Energy Costs Hit the Vulnerable - That's Us!

Anyone who has had polio knows we suffer cold more than most. So heating my home is important to me, and when costs soared, I wrote to my MP to see if anything could be done. His reply said he didn't think it was a great concern.

Well, it is to me - and I suspect many others. So when Age UK asked me to talk to an APPG about Fuel Poverty, I welcomed the chance. APPGs (All Party Parliamentary Groups) consist of MPs and Peers from all political parties. The one concerning Aging and Older People were meeting to discuss Fuel Poverty. This one is Chaired by Baroness Altman, a delightful person,, who let me tell all!

I did mention that patronising advice about "wear another sweater" only means we have more weight to carry around – but with fewer muscles to warm us, we depend on artificial warmth. And do 'they' really think we are going to leave windows open in cold weather? !!

We need electricity to light homes, run stairlifts, charge mobility scooters, operate life support and alarm systems, etc.

My story

As an 84-year-old Polio survivor living alone, disabilities caught up with me. With only one eye I can't read meters, so in January 2018 I talked to nice Andrew in Centrica's head office (they own British Gas). He arranged for me to go on their Priority Register, so British Gas would read my meters.

I set up a Direct Debit (amount suggested by British Gas), and in December 2019 their statement said "You are in credit £63.45."

The next statement from British Gas said I was massively in debt: **"Your new balanceis £6006.78"**.

Since this shock, I have been fighting for an explanation. Nothing British Gas tells me makes sense, especially a letter they send giving pages of supposed meter readings (in tiny letters), and offering £30 compensation. I thought this an insult.

The Financial Ombudsman got me a couple of thousand knocked off – but still no explanation.

A recent Ofgem report says I am not alone: **"some of the worst examples of poor practice included suppliers failing to read the meters of customers who could not do so themselves"**.

British Gas's Kate Collins sends me a 5-page email ending with "You are now free to resolve your complaint by other methods, such as through the civil courts. **This decision and its actions will then be not binding on British Gas and we consider the matter closed.**" Is British Gas above the law?

British Gas closes its email boxes, so the only way to contact them is by phone. You hold on for fifty minutes until you are cut off; then start the process all over again. Because of these long calls hanging on, I go over my free phone call allowance, so now pay excess phone charges each month asked.

Josh, from British Gas, visits to suggest I should have a Smart meter. I asked for a leaflet to study, and Josh said there weren't any. I explain I would be loathe to sign up without seeing what the meter dial looked like, to check if I could read it.

He offers to look at my bills to see if he could find out how the massive overcharge had come about, then tells me 4,000 electricity units had been overcharged.

A week later I open a letter from British Gas, expecting an **apology or explanation**.

Er – no. It says :

"We're about to apply for a warrant to enter your home"

This is threatening, unhelpful, and adds more stress. I ask British Gas to send someone to my home to sort this out, but they refuse. But they send an employee to knock on my door early one morning, who wakes me up. I send him away and tell him I don't open my door to strange men when dressed in my dressing gown.

Charities report worries

Then Age UK asks me to appear before an APPG meeting to tell my story. They want someone like me to tell MPs what happens to us. So I gather information from numerous charities, from the Polio Survivors Network to Jo Cole of the Tees Valley neurological charity; all express concern.

Macmillan say those with cancer need to keep warm; cancer means four out of five people are £570 a month worse off – and this was before the cost of living crisis started to kick in.

Jo asks “what good is an increase in benefits + pensions in April, when people have already had to cover the shortfall denied in 2021? **Ask the APPG what they would consider a reasonable excess death rate this winter due to fuel poverty?**”

Damian Bailey, Wolfson Research Fellow, expresses “concerns relate to understanding...the impact of sitting for hours on end passively in a chair in elderly folk who cannot afford to heat their homes over winter. Chronic exposure to cold is a vascular risk factor”.

Other Disability organisations ask variations of ‘how many ‘excess deaths’ are going to happen this winter, due to people being afraid to heat their homes?’

Jess, my ambulance driver, echoes concerns. . She takes regulars for renal dialysis, chemotherapy and radiotherapy – people who need warmth to survive.

She and her colleagues in South Central Ambulance Service are increasingly concerned how cold patients’ homes are when they go in to collect them. She says it is easy to see elderly patients are getting frailer and their health deteriorating.

Getting help

Advising us to ask charities for help is not on – we are a generation that fund-raises for charities, not one that asks others for help. I did try the Ombudsman and Citizens Advice Bureau, but as British Gas had knocked something off my bill, that let the company off the hook.

However, one charity that was extremely supportive was the **National Energy Foundation**. Beata Shaheen came to see me and took an enormous amount of time going through all the paperwork, commenting that it must have been extremely stressful for me.

After her supportive visit I think that I am going to have to get a good solicitor to take up my case – but why should I have to pay for this, when the problem seems to have been caused by British Gas not reading my meters correctly?

In the meantime I now think of costs as how many days of food they represent. I won’t be buying a new coat this winter; I wanted a new lipstick to give me confidence to face the APPG; it will cost the equivalent of three days’ food. So it’s a no-no.

Will I go to Prison?

I worry constantly about going to jail for non-payment of my bill. Jess picks me up to go to hospital; as she used to work in the prison service, I ask her what to expect. I find out that at 84, with all my medical conditions, I will probably be in the prison hospital wing. And I won’t have to pay for heating, lighting or food!

British Gas sends me an estimate for fuel consumption next year, saying for my one-bed property, my bill will be £5,500. That’s half my Pension.

What could be done

Could MPs head a non-Political group to sort out what can be done?

Talking to a top oil guru, on his way between Orkney and Houston, he reports there is a lot that could be done, but so many initiatives have vested interests – it needs an impartial body to sort out what is best for everyone.

We are grateful for government hand-outs, but know these aren’t going to cover all costs. And the 10 % pension increase, starting in April, won’t go far in paying fuel bills.

As Ofgem said, some of the worst examples of poor practice included suppliers failing to read the meters of customers who could not do so themselves, British Gas tells me their meter reader was unable to gain access. Strange – being disabled I am here all the time, and surely if someone was unable to gain



access, that should flag up an alert? I could have been dead for a couple of years with no one the wiser.

So could MPs do something to ensure all suppliers abide by a code for meter reading? And if a meter reader can't gain access, this is flagged up in case the client has had an accident

Many elderly people live in old buildings that are badly insulated and draughty. I had a surveyor in to see about insulation, but as soon as he heard it was a listed building he said nothing could be done. Could the APPG get local authorities to review restrictions on these buildings?

The system for charging for fuel needs to change and be easier to understand. Why penalize us for using less?

Three simple suggestions :

1. **Meter readers to flag up an alert if they don't get a response**
2. **Review restrictions on old and listed buildings**
3. **Fuel companies must give a clear explanation if a customer is faced with unexpected charges. And take the consequences if at fault.**

For anyone who is having issues with their Energy supplier, if my experience is any help, there is more on www.aftercancers.com/bg

Advising us to ask charities for help is not on – we are a generation that fund-raises for charities, not one that asks others for help.

So perhaps those patronising us with advice on hot water bottles and cups of hot tea might look at our actual problems before dishing out gratuitous advice. And as for my MP who tried to tell me this wasn't a problem

Does the NHS get its priorities right?

The NHS runs on forms

The NHS chucked out **Heat** and other dog-eared magazines lying around in Outpatients, and instead, we occupy our waiting time with a clipboard and form to fill in.

Handed to you without a smile; the Receptionist knows what's on the form, and she's not giving anything away.

Remember when every Secretary of State for Health spouted the same mantra: **cut back on time-wasting paperwork**. Then went on to devise more forms "to improve efficiency" No wonder doctors are always running late.

You fill in what seems to be the important stuff – then – you come to the **really important stuff**. What the NHS thinks is going to help you to get better.

Questions

First: work out what sex you are. I must admit I didn't know I had so many options – but will it make a difference which one I tick?

Then: read down a long list asking what religion you are. Now, this is where it starts to get real, and you wonder if you are here to see about your broken bones, or are you are worse off than you thought.?

These are REALLY important questions. It's no use being facetious – the NHS and umpteen nosey parkers really want to know.

What is your Ethnic background? Easy, I answer Other: Angle-Norman (totally true). That'll confuse the computer.

Do I consider myself Male/Female then a list of words comes next, which I am not sure I really understand? Suppose I tick the wrong box? Will I be chucked out of the ward I might be in

and end up somewhere alien? Decisions. Decisions. Why not just ask me which loo I want to use?

Instead I write MYOB and with any luck I will be out of there before the Receptionist tells me that's not acceptable.

Religion. Well, that used to be easy: I filled in C & E (Christmas and Easter) and that satisfied them. The hospital Chaplain would pass by my bed, and boy – did I make use of them. They knew everything that was happening in the hospital, and were a fount of knowledge if you needed anything done. Now, in a cost-cutting exercise the NHS is losing these useful people. **But no worries – now the NHS has it all down on paper, so no need to talk to someone.**

Dignity Then comes “do I consider I was treated with dignity”. No, what's dignified about giving blood and being punctured with a ‘sharp scratch’ Ouch!

Did I find it easy to complain? So even before this comes into my head, you are telling me I should be complaining. Hasn't the NHS got anything better to do?

Boot on other feet

And so it goes on. Weren't we promised that we were aiming for a paperless society? Fat chance.

But, query something about your treatment, and quick as a flash, back comes a jobs-worth quoting ‘data protection’. Now I actually read the act, many years ago, to see how it might impact on the company I was running. We were doing a lot of work with Government Ministries and such-like, but as long as one acted like a sensible human being, it seemed the Act made sense.

NOT the way it is run today, when it is used as a cop-out for doing nuffin. If anyone can tell me why the NHS can ‘lose’ 700,000 items of our personal data, yet refuse to talk to you if you phone to ask how a friend is doing, “because you are not a member of their family”; – they can't. It's just the lazy person's way of doin' nuffin.

And don't get me on the reasons why the NHS can be so secretive, yet Outpatient Receptionists can ask in a loud voice “what's your date of birth?” then “And do you still live at.....?” – questions which are tailor-made to help any Hacker sitting in a crowded room. It beggars belief from an organisation that says it keeps our data safe. Huh!

If I am brave enough you will see the next form I get used for the useful purpose of making paper airplanes. Should keep a crowded waiting room amused for hours. Whee!

By Verite Reily-Collins PSN Trustee, Health Journalist and owner of www.aftercancers.com



Editor: A useful video on how to make a paper airplane

<https://www.youtube.com/watch?v=veyZNYurlwU>

The following slides are from a presentation originally given by Lincolnshire Neurological Alliance to Dr. Martin McShane, Director of Commissioning & QIPP NHS Lincolnshire on 22nd August 2011. This Presentation was later updated and given to the new Clinical Commissioning Groups.

Lincolnshire Neuroscience Forum

First Meeting - January 1998

Led by Dr. Mandy Bretman

We learned Lincoln County Hospital held Neurological Clinics

ONE DAY A MONTH!

5 of the 8 Neuro Support Groups at this first meeting reported "This service is so poor we advise our members to go out of County"



1999 – LHA Neuro Statistics

Lincolnshire Health Authority Specification for Neurology
Top 16 Conditions in the County

At number 16 - Myasthenia Gravis - 24 patients



MGA Lincolnshire

"We have 112 members in Lincolnshire and not everyone joins"

FIVE Support Groups of the Neuroscience Forum

"We all have more than 24 members and our condition is not in the top 16!

There has to be something seriously wrong with LHA statistics"

Spring 2000

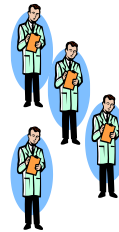
Lincolnshire Health Authority and Lincolnshire Neuroscience Forum

Surveyed General Practitioners

We asked 347 Lincolnshire G.P.'s "How many patients do you have with a diagnosis of one of the listed 32 neurological conditions?"



August 2000 - Lincolnshire GP's respond to Survey



Only 36 General Practitioners out of Lincolnshire's 347 replied

"We have **6,633** patients with a diagnosis of one of those 32 neurological conditions"

Population of Lincolnshire in 2000 was 634,300
6,633 patients a 10.4% response

How many if all GP's had replied?

1999 - How did LHA collect statistics?

Lincolnshire Health Authority admitted their figures came from extrapolating a population figure from the 16 nationally published figures



Sadly we learned for years national figures had come from adding up local health authority figures

SPECIALIST NEURO NURSES

Royal College of Physicians and Association of British Neurologists

Local adult neurology services for the next decade. Report of a working party. Published June 2011.

- Neurological disorders are very common,
 - accounting for about **ONE IN TEN GP Consultations**,
 - around **10% of emergency medical admissions** (excluding stroke) and
 - disability for **ONE in FIFTY of the UK population**.
- They include many different conditions of varying severity, some very common and others exceedingly rare, from migraine to motor neuron disease.

What are Lincolnshire's actual figures for these?

Since January 1998 LNA sought an improvement in Lincolnshire neurological services repeatedly pointing out that without accurate statistic evidence funds would NOT be allocated to Neurological Commissioning Plans.

13.8.2018 the HARG report - 20 years later - confirms a need for better data and more

January 2023 - Polio Survivors Network ask the Chair and Board of Lincolnshire ICB to please obtain more ACCURATE DATA for ALL not just SOME of their patients who are trying to manage their lives with a neurological condition.

Developing a health needs assessment for people living with neurological conditions in Lincolnshire

Summary Report [HERE](#)



HARG were asked by Lincolnshire County Council to undertake an independent health needs assessment for people living with neurological conditions in the county. A health needs assessment is a way in reviewing the current resources available to meeting the needs of a specific population. The review looked at adults over the age of 18, and young adults moving into adult services. It covered a range of neurological conditions, including stroke, epilepsy, Parkinson's and multiple sclerosis, among others. Lincolnshire County Council had previously undertaken a separate review looking at the needs of people with dementia, so dementia was not included within this study.

The aim of this report was to:

- Establish how many people in Lincolnshire are affected by neurological conditions, and how this compares with other parts of the UK;
- Review what we already know about the needs of people with neurological conditions;
- Explore what current services exist to meet the needs of people with neurological conditions;
- Understand the views of service users, their carers, voluntary groups and healthcare professionals on neurological services;
- Identify examples of good practice in services, but also see if any needs were not being met;
- Make recommendations to those who plan and deliver healthcare locally.

RECOMMENDATIONS.

There is a [need for better data](#) on the number of people affected by neurological conditions in Lincolnshire, and what services they need to access. This could be achieved by analysing GP records in the county.

There is a [need for a better understanding](#) of how neurological conditions link to wider issues such as social inequality. We suggest that this should be taken into account in future data analysis. This would help researchers and health commissioners better understand who may be at particular risk of neurological conditions, and plan services to meet their needs.

People in Lincolnshire with neurological conditions often have other health needs too. [Professionals in all health services need suitable training to ensure they are able to work sensitively with people with neurological conditions, recognise their needs, and signpost them to appropriate services.](#) This may help to reduce delays in diagnosis and treatment. One possible option to achieve this would be to incorporate awareness of neurological conditions within the 'Making Every Contact Count' initiative.

[A review of the reasons for emergency admissions](#) may help to identify changes that would help avoid emergency admissions. This could include changes to non-urgent services to help prevent problems, and better support for people in managing their health needs.

[There are gaps in local service provision for neurosurgery, rehabilitation and neuropsychology.](#) Health commissioners should consider carefully the balance between developing national centres of excellence for specific conditions, and the potential difficulties for patients accessing services, particularly in a rural county like Lincolnshire.

There should be a [review of how services inside the county and outside the county communicate with each other](#), to ensure that people living with neurological conditions receive continuous provision and are not allowed to 'fall through the gaps'; between services. This is especially the case where patients have been receiving specialist care outside the country but then transfer to community services. [There is a need for widespread, easy to access practical advice and emotional support.](#) Commissioners should consider setting up a network of peer support groups to extend and support the work of existing voluntary organisations for people living with neurological conditions across the county.

[Information about neurological conditions and services available should also be added to the training for Care Navigators](#) so that they can actively signpost patients and carers to appropriate services. specialist care outside the county, but then transfer to community services.

Carers for people with neurological conditions have specific needs. We suggest that there should be **further discussion with carer support services** in the county regarding the needs of carers for people with neurological conditions, and how they could **develop services to better meet the needs of this group.**

We all know that the NHS and social care services are facing substantial resource challenges at the moment. **Better communication between health organisations, voluntary sector organisations, patients and carers should help to ensure everyone understands the challenges being faced, and help identify changes that could improve services for example, better support for service users in managing their own needs, and ensuring that the neurological conditions are taken into account when planning other local health initiatives, such as the development of Neighbourhood teams.**

Editors comment - Polio Survivors Network Committee members between us have over 35 years of personal and occupational experience of the issues that polio survivors - after many stable years - have had trying to obtain accurate assessments of their new and unexpected symptoms and issues and assistance in managing our newly changed post-polio lives.

This includes Colleges of Medicine not teaching enough facts about how the polio virus affected our bodies and most often also not including the fact that there is a later stage to having polio after many stable years to its students.

It also includes issues with Manual Muscle Testing. This was developed in response to the need to assess muscle strength losses during the polio outbreaks in the early part of the 20th century. The development of this method is credited to Wilhelmine Wright and Robert W. Lovett MD 1915. In the 1940's Henry and Florence Kendall published a book called "Muscle Testing and Function" which defined specific muscles tests to isolate each specific muscle.

Due to time constraints in medical appointments a routine of a few single action tests for each limb was undertaken. If no weakness was found at the first test then the tester moves on.

Following a fall in October 1988 I spent the next seven years being assessed by this method was continually told there was nothing wrong with me. As a strong willed do not give up polio survivor who was becoming weaker year on year this was extremely hard to cope with.

At an Orthopaedic medical appointment on the 25th November 1995 with a Locum I had not met before gave me the results of my MRI saying 'I am glad you are better'. I responded 'I am not better I have continued to deteriorate for the last seven years, I had polio as a child has that anything to do with this?' The locum doctor immediately looked at the front of my file, told me that he had had another patient last year say the same and although he knew little about it there were later effects to having had polio. My prior waist down paralytic polio was at last in the equation.

I started my research into polio and its later effects that day and have not stopped since. It was not long before a huge penny dropped. I had passed a medical for the Police in 1969 when I could not run. No health professional would write facts on our medical records that he/she did not believe were true... there had got to be something wrong with the form of assessment used.

<p style="text-align: center;">Self assessment of two tests with no pressure against action</p> <div style="display: flex; justify-content: space-around;"> <div style="text-align: center;"> <p>Straight Leg Raise Repeats</p> </div> <div style="text-align: center;"> <p>Arms - Lift Item and Sustain</p> </div> </div> <p style="text-align: center; color: red; font-weight: bold;">N.B. Decline WAS NOT seen by the single action testing.</p>	<p style="text-align: center; color: blue; font-weight: bold;">Manual Muscle Testing. Two confirming statements.</p> <p>Lauro S. Halstead MD - May 2002 - Director Post-Polio Program, National Rehabilitation Hospital, Washington DC, USA.</p> <p style="color: red; font-weight: bold;">If done only a single time, it can give an erroneous idea of the true muscle strength and endurance.</p> <p>Fred Maynard, M.D. - May 2002 - Marquette, Michigan, USA, President Board of Directors, Post Polio Health International.</p> <p style="color: red; font-weight: bold;">"You have done a brilliant job of describing a real problem for polio survivors and professionals that is, the limitations of the Manual Muscle Testing"</p>
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CO-PRODUCTION WORKS AND SAVES TIME AND MONEY if....

ALL those EXPERIENCED in the GIVING and RECEIVING of the NEW PROCEDURES are INVOLVED from the START of the PROCESS

REQUEST FOR INFORMATION

CONSTANT PAIN

We are not medical professionals. You will need to make an appointment with appropriate medical professional/s to discuss your issues. We accept there are very few health professionals who understand and are knowledgeable on the issues polio survivors experience. The slide on the right is from one of our presentations showing how you might get a reduction of pain and fatigue levels by pacing and resting activities and also adding in the use of aids and assistive devices.

ACTIVITY BEFORE AND AFTER CHANGE	Time of Day	Time Doing	Time Resting	Pain Level	Fatigue Level
Getting up, showering and dressing	8.00 10.00	30 mins	90 mins	3	5
Changed to showering Underwear and calipers Top Clothes Less pain/fatigue Saved time resting	8.00 9.00	15 10 5 30 mins	10 10 10 30 60 mins	2	3
Walking round one shop pushing trolley	11.00 3.15	15 mins	180 mins	4	7
Doing the Town Centre using electric scooter, walking in shop where necessary, no bag carrying. Gained time doing, saved time resting Less pain/fatigue	11.00 4.00	120 mins	60 mins	2	4

We have learned that every time we experience a new slight loss of the way we do an action that it becomes our NORM. Experience has showed that this often means we will answer the Can you do x questions with a YES because we CAN do the action. The issue here is that if we do not tell the health professional HOW we do that action now they could miss a very important fact that they need for their assessment. For instance if your legs are weak they often assume you will pull yourself up with your arms. But maybe like me you have to push yourself up. I am sure if you think about how you do actions you will find you are now doing many of them in a different way than is normally expected.

Here are a few questions to ask yourself. If you have cooked a large saucepan of chopped vegetables do you still put on the lid and tip the water out... or like me do you now first put a colander in a saucepan in the sink close to one edge. Then slide the saucepan of veg across the hob and onto the work surface and up to the edge of the sink and carefully and slowly I tip the saucepan so that the contents [hopefully] all go into the colander.

Getting up a flight of stairs. Do you walk up as normal folks do, or do one step at a time one foot first? Do you pull yourself up holding onto the banister rail? Do you stop halfway to get your breath back? If you need to take items up the stairs are you moving them up a few stairs at a time as you go? Or might you be sitting on your bottom and pushing yourself up stair by stair with your arms resting on the way.....

How about turning over in bed? Do you just turn in your sleep or do you have to wake up to turn yourself by holding onto the cupboard next to the bed or the handle of the mattress? What happens if you sleep in a hotel or hospital bed and the [way you do this] is not available? Reminder here about Snoozle sheets which were developed for pregnant ladies to help them turn over in bed. I have been using one for over 12 years. As picture they are a tube of material with very shiny material on the inside and as you turn one layer slides on the other, www.thesnoozle.com



My Polio Life - A self assessment tool that we developed over 20 years ago gives you a few ideas of actions of daily living to think about but we will all have many more actions to add. Think about how you do the action now? How did you used to do this? What has changed? The change is the information you need to explain to health professionals so that they can find out why you have changed the way you do the action. Until I started to think about the how did I do things now I had no idea how many actions I had adapted. In 2004 I had had the basic physiotherapist assessment of my muscles. I then told her what my self assessment had found and asked if she could tell me why I had had to change the way I was doing these actions. The first one was the fact that I realized for at least three years I had been scrambling eggs using elbow rotation. She now examined more than just the normal actions for arms [testing the actual actions for the task I had referred to] and found that the supinator muscles in my wrist were now extremely weak. I looked back over the last five years of my medical records and all muscle tests of my arms had just been the basic tests and been recorded as normal. The Physiotherapist then looked at how did I get up off the floor [writing on my records uses back extensors and hamstrings - I would get onto my hands and feet in a ^ position walk my hands back to my feet and stand.

<https://poliosurvivorsnetwork.org.uk/new/wp-content/uploads/2021/07/My-Polio-Life.pdf>

Did you know that The Brain Charity holds free social activities for anyone affected by neurological conditions?



<https://www.thebraincharity.org.uk/events/>

Polio Survivors Network is a member of The Neurological Alliance.

If you have not yet signed their petition calling for governments across the UK to **#BackThe1in6** and deliver real change for people with neuro conditions we encourage you to do so

<https://tinyurl.com/BackThe1in6>

THE NEUROLOGICAL ALLIANCE

1 in 6 people in the UK live with a neurological condition

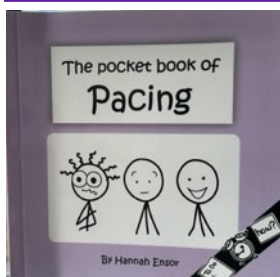
but there simply aren't the workforce or services to provide the support they need.

#BackThe1in6

A Call For Your Help

Can you offer advice for our newer members who are looking for: help regarding:

- (1) Falls are becoming a problem for me (I've broken a good number of bones), I use a wheelchair outside the house now and a crutch inside, the only thing that seems to help is a Velcro knee wrap round knee support, any strategies/articles on this would be interesting.
- (2) Constipation seems to be linked to polio in a number of ways like not exercising, muscle wastage and possibly Vagus nerve damage, any strategies/articles/ideas to help would be of great interest.
- (3) How have you got on with leg braces / KAFO / AFOs etc please?



A helpful book for Polio Survivors

The Pocket Book of Pacing

by Hannan Ensor

96 pages - 110mm x 110mm - £5.50



Toni Writes ...

My short piece in this issue picks up on one of the comments below as we need your help. Please can as many as possible provide us with your polio experience. It doesn't have to be a long piece (unless you want it to be). Maybe think about including things like how you were affected when you had polio, how your life has been health wise, what you've accomplished e.g. married, children, career, travel, etc, any difficulties in older age as a polio survivor, what support you'd like to see for polio survivors. Feel free to email psnadmin@poliosurvivorsnetwork.org.uk with a written piece.



Or join Roy, Sue and Florence in providing your experience by a short video (audio only is fine too) you can find their experiences in our PSN library and on our website. It is very simple to do, just upload the recorded file via this link <https://bit.ly/3D8MQKQ>

If you are not able to record a piece but would like to, I can provide you with a Zoom link and you can simply start telling your story. When finished a file is automatically sent to me. Just email me for more information so you can get started.

I can't wait to get to know you better.

Take care

Toni x

Email	psnadmin@poliosurvivorsnetwork.org.uk
Post	PO Box 954, Lincoln, LN5 5ER
Website	www.poliosurvivorsnetwork.org.uk
Phone	01522 888601

From our readers:

By reading the newsletters, it has enabled me, and my wife, to understand the reasons why my periods of fatigue and the wasting of my right leg, is not just 'in my head' and due to a heavy clutch but that so many others are in the same boat. Thank you once again for all your efforts.

In this world of no definite diagnosis & no definite meds, which I know well is to try & kill the pain, use whatever mechanical aids you can get. Positivity!!! Works for me, I know it may sound stupid but no matter how bad I feel in the morning, I can't wait to get out for an hour or so on my electric assist recumbent. So far I've not yet had pain whilst riding summer or winter. The strangest things may help.

Keep up the positives online exercise needed.

I would like to see in the magazine more chat from survivors how & what they are doing to cope. For me it's been over 10 years since I first approached officialdom, still not got a positive idea of what's wrong & not enough medication or alternative treatment.

Just to comment on I how I handle getting up after a fall which might help others, my wife cannot physically help me but we have found a rechargeable bath lift (on Amazon) that is easy to get on if I'm on the floor and raises me high enough for it to be like getting off a chair, allowing me to stand.

Florence Lunde's Polio Life

PP (prior to polio) I was an athlete, went to sleep away camp every summer and rode horseback. I was being groomed to go to a special music high school in New York City. All that changed in September 1953. I came down with a combination of spinal and bulbar polio at the age of 12 1/2. I was paralyzed from the neck down and put in an iron lung. Most of my early memories are very painful to remember for example, I received the sister Kenny treatment which were hot packs wrapped around my limbs. They were a dark grey material that itched and after that came terrible stretching of my muscles that hurt horribly. I remember when I was transferred from the acute hospital to the respirator centre in another hospital in New York City. I was in the iron lung placed into a truck and away we went. When I got to the other hospital I remember going down long corridor looking up at the ceiling with the lights and looking at the physician pushing the iron lung. It was very frightening to me. I didn't know where my mother was seeing as she came along with me in the truck. Now as an adult, I assume she went to fill out the paperwork but at the time I had no idea where she went.

I was slowly weaned out of the iron lung and was given a cuirass which was a chest shell with the hose in the middle going to the respirator mechanism. I was also placed on a rocking bed which was the worst. I always feared I would slip off the end. By the age of 13 I did not need to use a respirator at all until my late 20s at which point Dr. Augusta Alba told me to use it in the evening with a mouthpiece for 20 minutes to expand my lungs. I followed her directions and did quite well for about 45 years and then started needing night time ventilation. Today I use the vent with a mouthpiece from about 5:30 PM until the next morning when I get up at 7:30 AM.

During my teenage years up to my early 30s It was very important to me to be just like everyone else. I started smoking at the age of 16 because everybody else did and this was something I could do just like everyone else. I remember one winter I washed my hair and went out with it wet because so did every other teenager, however I came down with pneumonia when the other teens did not. Other than that my health was good. Once I started to understand that I was not like every other teenager and that I needed to take care of myself and not try to imitate what other people did my health improved I had fewer colds and bronchitis every winter. Of interest is that since I moved to Florida I think I have had two upper respiratory infection in the 15 years I'm here.

I was on home instruction for the seventh, eighth, and ninth grades returning to regular high school in the 10th grade. I was the first disabled student to go around from class to class just like everybody else. They appointed another student to take me from classic class and she got credit. Back then they did not have motorized wheelchairs and I was not able to push the manual wheelchair so a student took me from class to class.

Speaking of motorized wheelchairs, the first time I got into the motorized chair I went up and down the corridor of the hospital and upon returning to the occupational therapist I burst into tears saying "I have been let out of prison." I had freedom now I could go and come whenever I wanted to, go where I wanted to and do what I wanted to. I was not dependent anymore on people taking me someplace. For the first few months of using the motorized wheelchair I could not sit still I had to constantly move. For example my husband loved to wax his car I would go and sit with him while he waxed the car. All of a sudden I had to move I remember saying to him I will be back and I took off went around the block and came back. I don't remember how long this behaviour lasted but I would venture a guess to say a few months. I went to New York University for my undergrad and graduate work in Speech – language pathology. I worked at an inner city hospital in New York city for 29 years in the department of rehabilitation medicine and my area of focus was patients who sustained a cardiovascular event demonstrating language dysfunction. I retired because my body couldn't do it anymore. I was constantly tired & cranky.

God has played a major role in my life. He took away my anger, bitterness, my depression and filled me with his Holy Spirit and gave me a newness of life with joy and peace. My husband and I started a ministry for people with physical disabilities in New York City called His Abundant Love Ministries. It was a once a month group that met for 29 years before we retired. We

saw many people saved and lives changed. Our television show on Bronx Net, won three Beta awards. I have also received my graduate certificate in Christian ministry from the King's seminary. I have authored three Christian books. The first one is God's word for you which focuses on how God brought me through the early days of polio, experiences I had, including peoples reaction to me now that I had a disability. The second and third books are sister books: Digging Deeper: the Devotional and Digging Deeper: the Bible study. They are organized by theme. All purchasable on Amazon just type in my name.

My husband was a paraplegic from a construction accident. We were married for 42 years before he passed away in 2013 from dementia. We travelled extensively using travel agencies for the disabled. A funny vignette happened in Israel. The elevator was so small that a wheelchair user had to remove the foot pedals in order for the door to close. Well this one young lady couldn't put her foot pedals back on fast enough when the elevator stopped for her to get out so she kept going up and down until somebody was able to help and all the doors open. The rest of us just sat and waved to her as she came to our floor it was so funny at the time.

I am now 81 years of age and post polio syndrome has done a number on me. Not only am I constantly tired, but I have lost strength, my balance is off and the fatigue is at times overwhelming. Whereas I used to live alone before I got married and took care of myself completely, now I need a caregiver to help me with all ADLs. There are times when it wears me down usually when I think back to what I was able to do and now cannot. I am a full-time motorized wheelchair user and as I said I use a vent at night.

The support I need as I get older is that I need more and more help to live independently. There has to be a system set in place where people that worked all their lives, making a good salary with good retirement benefits to receive some financial aid to pay for the caregiver. At the time of this writing in Florida, USA the going rate per hour is \$23 which gets costly.

Editor: See Rev, Florence Lunde's website www.florencelunde.com

Useful Resources

- International Ventilator Users Network
www.ventnews.org
- Disabled Motoring UK
www.demukdiscounts.co.uk
- Pain UK
www.painuk.org
- National Voices
www.nationalvoices.org.uk
- Neurological Alliance
www.neural.org.uk
- Rare Disease UK
www.raredisease.org.uk
- End Polio Now – Rotary International
www.endpolio.org
- European Polio Union
www.europeanpolio.eu
- Post-Polio Health International
www.post-polio.org
- PA Polio Survivors Network
www.papolionetwork.org
- Polio Quebec
www.polioquebec.org/eng/
- Polio Survivors of Marin
www.facebook.com/groups/163909760771171
- Atlanta Post-Polio Association
www.atlantapostpolio.com
- Nebraska Polio Survivors Association
www.nepolioorg.ipage.com
- Polio Australia
www.poliohealth.org.au
- Word-Wide Fellowship of Polio Warriors
www.poliowarriors.org

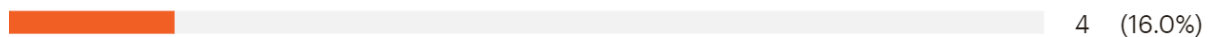
A Quick Message From The Trustees

Thank you to those who have already responded to the email sent out regarding our 2023 Annual General Meeting. We really appreciate your feedback to help us plan ahead.

Here are the results so far:

“We are beginning the planning for our Annual General Meeting in 2023, please let us know whether you would prefer to attend:”

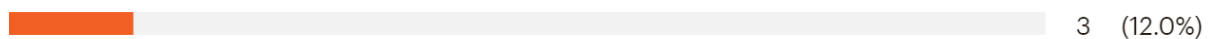
In-person (Lincoln, UK approx July 2023)



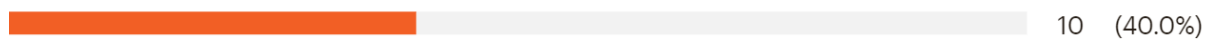
Online (Zoom)



Hybrid (located in Lincoln,UK with option to join by Zoom)



Sorry - I will be unable to attend PSN AGM 2023



For anyone who has not done so please contact us to let us know your preference.

We've joined **Making A Difference Cards** – a site that lets you make donations for Polio Survivors Network with every Personalised Card or Ecard you buy. Support Polio Survivors Network and help us raise as much as possible.

<https://gb.makingadifference.cards/supporting/polio-survivors-network>

help support Polio Survivors Network all year round on making a difference cards

<https://makingadifference.cards/supporting/polio-survivors-network>

Management Committee [Trustees]

Chair - Simon Parritt - simon.parritt@poliosurvivorsnetwork.org.uk

Zsuzsanna Snarey - zsuzsanna.snarey@poliosurvivorsnetwork.org.uk

Treasurer, Newsletter Editor - Hilary Boone - hilary.boone@poliosurvivorsnetwork.org.uk

Trustee - Verité Reily-Collins - verite.reilycollins@poliosurvivorsnetwork.org.uk

Trustee/s - Vacancies please contact Toni for more information

Operations Team

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PSN Admin, Enquiries and Website - Toni Dunlop - psnadmin@poliosurvivorsnetwork.org.uk

Printing - Imprint Colour Printers, Lincoln

With grateful thanks to the generous legacy from Ms A Brown, we are able to make membership **FREE** whilst our funds remain above £10,000.00

Website www.poliosurvivorsnetwork.org.uk

Write to us at PO Box 954, Lincoln, LN5 5ER, U.K.

Email psnadmin@poliosurvivorsnetwork.org.uk

Phone us on 01522 888601 - will ring you back when we access our messages

UK Members - receive newsletter by post and/or email (overseas members newsletters by email only)

All donations, small or large, towards our work are gratefully received

Donate by **cheque** to Polio Survivors Network

by **PayPal** to treasurer@poliosurvivorsnetwork.org.uk



By **PayPal** donate link: <https://bit.ly/2KzyAyE>

giftaid it

The Gift Aid scheme. Charities can reclaim an extra 25% in tax on every eligible donation by a UK taxpayer. This 'transitional relief' does not affect your personal tax position. You must pay tax at least equal to the amount reclaimed on your donations in the current tax year. If you pay tax at the higher rate, you can reclaim tax relief on your gross donation at 20% (i.e. the difference between the higher rate of tax at 40% and the basic rate at 20%). If you have not filled in a current Gift aid form please contact us and we will email/post you one. Thankyou.

The most accepted articles by NHS professionals we have found are:

PatientPlus article POST-POLIO SYNDROME

Written by U.K. Doctors for Doctors

<http://patient.info/doctor/post-polio-syndrome>

NB Respiratory and Sleep Problems Section very informative.

GOOD ANAESTHETIC ARTICLE - English version used by many PPS Groups

POLIO PATIENTS AND SURGERY - Information for health staff.

Lise Kay, MD, Surgeon PTU – Danish Society of Polio and Accident Victims

http://www.europeanpolio.eu/documents/13642_Polio_operation_eng_TRYK.pdf

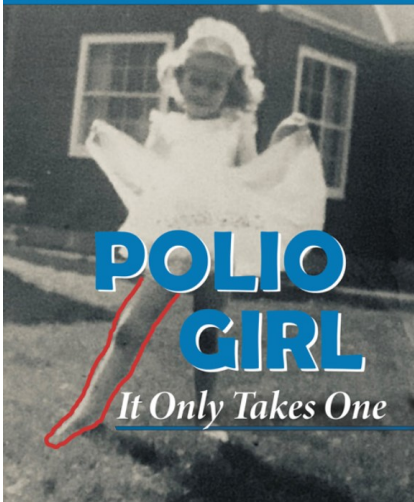
Printed copies on our headed paper with permission are available.

Editors Note: Articles from Polio Survivors and Health Professionals welcomed

Naidex

22ND / 23RD MARCH 2023
NATIONAL EXHIBITION CENTRE
BIRMINGHAM

Susan L. Schoenbeck, MSN, RN



Sometimes reading a fellow polio survivor's experiences helps a person gain perspective on their own life. There is so much we survivors were cautioned to not reveal. As a nurse, I have heard anguish in the voices of polio survivors who are maligned and their complaints dismissed because the doctors do not understand the often hidden, long-haul symptoms of polio. The book is set forth in a way that polio survivors can find sections about the symptoms that bother them and show the health care provider the underlying research supporting their complaints.


The book comes with an extensive bibliography and reviews from a polio doctor who had childhood polio, family physician, social worker, psychology instructor, physical therapist, orthopedic physician assistant and registered nurse.

I wrote my latest book, POLIO GIRL: It Only Takes One (amazon.com; released July 2022) to increase the understanding of everyday people about how polio affects a child and a family and to educate healthcare professionals. In the book, I tell my stories of leaving my body as a child when the pain was unbearable or treatments hurtful. The book bends two ways. One, it is the story of my family who was told their infant with polio would never walk. Two, it is a resource manual for polio survivors and healthcare personnel who can step-up-to-the-plate and identify acute polio and post-polio symptoms and meet patient needs.

Experiences of Polio Survivors

Some of our members wish to share their experiences by video – we hope they help you too. If you would like to share your experience please contact us and also see our PSN Library for more written experiences. Videos by Roy Burnham, by Sue Robinson in two parts and another from Rev. Florence Lunde. More being added later in January.

PSN are trialling a [CHAT BOT](#) on the bottom right of our Home Page.

Click on this  and the following will open:-

PSN Chat Bot has joined the conversation.

Hi, Welcome to Polio Survivors Network!

[Send a Message](#)



Polio Survivors Network would like to say a BIG THANKYOU to Val Scrivener for her wonderful photo cards over the years. Members, thank you for purchasing them and raising funds for our charity.